

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Washington -- Supporting Family Caregivers in Ethnic Minority Communities

Issue: Expanding Access to Supports for Families with Persons with Alzheimer's Disease

Summary

The State of Washington initiated a multi-faceted effort in three areas of the state to increase access to supports for diverse populations who are caring for a relative with Alzheimer's Disease. Working with local community organizations, the state used a combination of targeted outreach, community education, case manager advocates, and culturally sensitive diagnostic assessment procedures to significantly expand caregiver supports for diverse populations.

Introduction

The State of Washington's population is becoming increasingly diverse. Effectively reaching diverse groups of people in need of services is a challenge faced by many public programs. The state initiated effective outreach efforts for families of people with Alzheimer's Disease after observing that ethnic minorities were being underserved by its state-funded respite program.

This report briefly describes Washington's initiatives to reach persons in local Chinese, Korean, Hispanic, and Native American communities who need help caring for a family member with Alzheimer's Disease. The report is

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based on interviews with state and local staff, written materials obtained from the state, and written materials obtained from the U.S. Administration on Aging,

which funds demonstration projects serving persons with Alzheimer's Disease.

Background

Since 1989, Washington State has operated a state-funded respite program managed locally by Area Agencies on Aging. The program supports families caring for persons who need continuous care or supervision and who would require nursing home placement in the absence of

caregiver assistance. While the program is not limited to caregivers of persons who have specific conditions, at least 45 percent of families in the program are supporting a relative who has Alzheimer's Disease.

The program, however, was struggling to serve persons in ethnic minority communities, some of whom held perceptions of Alzheimer's Disease that made them reluctant to seek assistance. For example, some people believed Alzheimer's Disease did not exist in their communities; others believed an older person with advanced stages of dementia brought shame upon the family and therefore his or her condition must remain a private matter. Thus, the state needed to increase awareness of the prevalence of Alzheimer's Disease amongst diverse groups of older people and change community perceptions so families would be willing to seek supports. The state also needed to make existing service programs more sensitive to diverse cultural values.

The state of Washington obtained funding to increase the capacity of its caregiver support programs, including its respite program, to better serve ethnic minority communities from the Alzheimer's Demonstration Program. This program makes grants to states on a competitive basis to develop new community models for supporting persons with Alzheimer's Disease and their families. The U.S. Department of Health and Human Services' Health Resources and Services

Administration initially managed the project, which was later transferred to the Administration on Aging in the same department.

Intervention

The state's initiative had four objectives: 1) to increase service providers' understanding of Alzheimer's Disease and the specific needs of underserved populations; 2) to provide seed money to local agencies to develop culturally sensitive service models; 3) to increase the number of individuals and families from ethnic minority communities who receive respite care; and 4) to increase access to diagnostic and referral services for ethnic minority individuals. To develop new models of support, the state made competitive awards to four local projects that each targeted their efforts on one of the underserved population groups, including Chinese, Korean, Hispanic, and Native Americans.

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Each ethnic community expanded the roles of existing ethnically based organizations to begin providing new forms of services – namely, respite and other caregiver supports. These agencies worked with experienced local organizations to develop programmatic expertise. The Chinese Kin-On Community Health Care project worked with King County Aging and Disability Services in the Seattle area. The Korean Women's Association worked in partnership with Pierce County Aging and Long-Term Care in the Tacoma area. Four Native American tribes collaborated with the Northwest Washington Area Agency on Aging. In the Hispanic community, a community health center with extensive experience serving Hispanic Americans but with limited knowledge of older people with disabilities collaborated with a large adult day health provider committed to increase services to Hispanic older people.

Due in part to the differing auspices of the local agencies, approaches to providing caregiver supports varied. The Korean Women's Association, the Kin-On project, and the Northwest Area Agency on Aging hired outreach workers who often went door-to-door in ethnic

minority communities to find families caring for persons with Alzheimer's Disease and encourage them to use respite services and other supports provided by the projects.

The partnership between the Sea-Mar Community Health Center and ElderHealth Northwest Day Centers created a different model for enhancing services to the Hispanic community. The traditional Hispanic agency (Sea-Mar) hired staff called client advocates, whose outreach role was similar to that of the other programs. The client advocates also worked in the ElderHealth Northwest Day Centers to help integrate Hispanic participants into the adult day health programs by adapting program components (e.g. activities, celebrations and meals) for cultural appropriateness and by functioning as cultural and linguistic translators. Client advocates also assisted with practical functions such as transporting people to the center and to doctors' appointments as well as teaching Spanish to staff.

All four projects were supported by the University of Washington Alzheimer's Disease Research Center, which had experience conducting in-home diagnostic assessments of persons to determine the presence of Alzheimer's Disease. As part of this initiative, the Research Center modified its assessment protocols to reflect the cultural sensitivities and languages of each of the four target populations.

Implementation

Several challenges were encountered in implementing this initiative. One challenge was the need for service providers to gain the trust of the communities in which they were working. Each local agency found it essential to hire outreach staff who were not only of the same ethnic group as the target population, but were from within the community itself.

Another challenge was to overcome the general lack of awareness about Alzheimer's Disease. Each of the local projects found that one of

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the strongest barriers to delivering services to their target populations was the different cultural

perceptions of Alzheimer's Disease. For example, in one dialect, the Chinese translation of Alzheimer's Disease means "crazy and dumb" disease. All projects placed a high priority on conducting general community education and on working with community leaders and physicians.

Finally, each project found that significantly more time was needed than originally anticipated to conduct community development activities that eventually led to program enrollment by families. Of all of the types of outreach conducted by the projects, the most time consuming strategy, face-to-face contact, was the most successful.

Impact

Washington's initiative has created several enduring outcomes. Community education, outreach materials and diagnostic assessment tools have all been developed and tested to reflect the cultural sensitivities of each of the target populations. The demonstration sites have also served as an unexpected point of entry into other programs in the state's larger home and community service system. The Hispanic Client Advocate model for outreach and integration into traditional service programs has been replicated in other parts of the state.

With the end of the demonstration project and timely beginning of Washington State's Family Caregiver Support Program in 2000, several services that were developed during the project were able to continue through a variety of

funding sources (e.g., the state's Medicaid HCBS waiver program, private funds, National and State Family Caregiver Support Program funds). The Korean Women's Association adult day program, which serves people with dementia and other conditions, has continued to date.

In addition, the Kin On Community Health Care project expanded their focus from Alzheimer's/dementia to general family caregiver support. The client advocate continues to link the Northwest Area Agency on Aging to local Native American tribes, with an expanded focus on caregivers of people with any condition. The Hispanic client advocate model, developed by Sea-Mar Community Health Services, continues to be utilized by numerous nutrition, senior center, and adult day programs throughout the State of Washington.

Contact Information

For more information about the State of Washington's efforts to enhance caregiver supports available to families in ethnic minority communities, please contact Hilari Hauptman of the Washington Aging and Disability Services Administration at (360) 725-2556 or haupthp@dshs.wa.gov, or Lynne Korte of the same agency at (360) 725-2545 or kortelm@dshs.wa.gov. Information about the Alzheimer's Demonstration Project can be found at <http://www.aoa.gov/alz/index.asp>.

Some Discussion Questions:

What different outreach approaches may be necessary for other populations or other communities?

What challenges arise when agencies that serve diverse populations expand their role to serve family caregivers?

One of a series of reports by Medstat for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series is available online at CMS' Web site, <http://www.cms.hhs.gov/promisingpractices>. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.